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AUTHOR Biklen, Douglas
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ABSTRACT

This report describes family support through the experiences and testimony of eight families. The eight families, who had children with very difficult health and behavioral problems, were participants in the Macomb-Oakland Regional Center's Family Support Program, near Detroit, Michigan. Interviews were conducted to give voice to the families who were using family support, to understand their perspectives on their experiences with it, and to see its positive aspects and its dilemmas. The report examines the family situations, by looking at the conditions of the children, the parents' view of their child-rearing role, the family's acceptance of the children's handicapping conditions, leisure time activities, and foster parents' views of their work as both a job and a responsibility to a child they grew to love. The families' perceptions of the role of the family support program are also examined. Families indicated that they wanted: an alliance between caseworkers and families; a caseworker that helps with the child but does not intrude on the family; recognition from the caseworker that parents are knowledgeable sources of information about the child; an ally with whom to transform the system; and provision of equipment, medical care, cash, and respite care. (JDD)

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In Support of Families

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In Support of Families

by

Douglas Biklen

Center on Human Policy

Research and Training Center on Community Integration

Syracuse University

724 Comstock Avenue

Syracuse, New York 13244-4230

(315) 443-3851

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*With the exception of the organization name, Macomb Oakland Regional Center, all names of individuals which appear in this report study are pseudonyms.

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I. INTRODUCTION

> They didn't have heat, the water was dripping from the faucets, they didn't have hot water. Their baby had a trach. They didn't have a vacuum. The roof was leaking. (There had been) terrible storms and the back roof had collapsed on the house. The basement was terrible, filled with mold. The flooded basement ruined their furnace and their washer and dryer. The whole bit. You name it, they had it.

So began my introduction to the Macomb-Oakland Regional Center's family support program just outside of Detroit. Two family support case workers were telling me about the first of eight families that I would be interviewing as part of a study on family support services. In each case, the children had either very complex and/or life threatening medical conditions or extremely challenging behavior such as biting, frequent moaning or other verbal outbursts, or hitting. I had asked the family support staff at the Macomb Oakland Regional Center to arrange extended interviews for me with eight families (Table 1 provides a brief description of the families and children), all of whom had children with very difficult problems, the kind of difficulties that might be expected to force them into nursing homes, extended care hospitals, or institutions that specialize

Family	Child	Character of supports used	Family Support issues represented
Wilson/Waters birth family	Sholanda: infant daughter with multiple disabilities died recently	[illegible]sic health and [illegible]afety: heat, plumbing, electrical -nursing supervision [illegible]spite	-large, low income family -history of involvement with public assistance -hospital discharge planning -inter-agency cooperation (or lack)
Rozak birth family	Timmy: son 3 year old, born with multiple disabilities	-purchased nursing [illegible]e -tra[illegible]portation -housing -identification of specialists willing to treat -Sub[illegible]idy	-single parent with no natural support system -NICU hospital discharge planning -extraordinary supports initially weaned over time -benefits of early intervention on growth and development of child in family vs. facility
Julian birth family	Nicky: son normal development until sudden onset of severe degenerative condition. Became ventilator dependent before death	-in-home nursing -major equipment and supplies -adapted transportation	-volunteerism -basic strengths of natural supports -health care insurance coverage -highly specialized technology in home care
Gardner birth family	Mathew: adolescent with label of autism, has shown maladaptive behavior challenges	-in-home trainer -specialized sitter	-role of supports in deflecting out-of-home placement -parent role in advisory capacity to public mental health programs

Figure 1, p. 1

Stone foster family	Kerry, Noah, Toni: adolescent with severe physical disabilities, behavioral challenges	-in-home trainer/consultation -respite -interdisciplinary team program planning & support	-longevity of foster care -willingness of foster parents to open home to youngster with severe disabilities -strong natural supports, friends
Lisswell foster mom	Tasia, came from ICF/MR and previously a nursing home	-purchased in-home staff support -interdisciplinary team involvement in program planning and support	-role as direct care staff led to attachment potential source of foster family -single person with no prior parenting experience as foster parent
Cleary foster family	Semantha, Brian: 4 foster children and adopted daughter all with severe multiple disabilities. All were formerly residents of large facilities	-in-home supports arranged by family through budget allocation directly to family -interdisciplinary team planning	-willingness of families to open their homes -several developmentally disabled family members, while not ideal as a "model", is far superior to institutions and nursing homrs
West	2 foster children Tina and Nancy, raised from pre-adolescence to early 20's	-behavioral trainer/consultation -interdisciplinary team planning & support -medical support -respite	-willingness of family to open its home -willing to accept person with extreme self abusive behavior -strong natural supports -openness to learning effective child rearing strategies for child with difficult behaviors

Figure ... p.

in behavior control.

Family support programs are intended to help families keep their children or foster children at home rather than in such a congregate setting. A principal reason for institutionalization or other out-of-home placement is the lack of support services available to families, including schooling, preschool and daycare, respite care, medical assistance, transportation, financial assistance, and attendant services (Taylor, Biklen, and Knoll, 1987). The intent of this study was not to further document the need for assistance to families or to catalogue the services that comprise family support, although further light would be shed on both. Rather the study was to give voice to the families who were using family supports, to understand their perspectives on their experiences with it, to see its positive aspects but also its dilemmas.

I have organized my report around two central questions: Who are these families (ie. what are the conditions of the children, are they single or multiple adult families or both, how do the parents view their roles in child rearing)? And, what do these families want from a family support program? Related to the second question, we of course examine what parents get from the family support program and how they feel about it. But our central questions concern who the families are and what they want. From these questions we can derive lessons for family support policy.

II. WHO ARE THE FAMILIES?

The children:

Typically family support guidelines prescribe the services for people with certain disability classifications (e.g. severe retardation, autism, severe behavior disorders, multiple handicaps) or with the disability classification and particular circumstances such as vulnerability to being institutionalized, absence of involved family members, danger of self abuse or abuse by others, or a void of other community programs. At the same time, some people are presumed ineligible or "unservable" because of the severity of their needs, for example complicated medical conditions and extreme acting out behavior.

The sample of eight families represented the extremes of those who might be eligible for support (see the brief descriptive table provided by MORC). In other words, we asked to meet with families (birth, foster, and adoptive families) whose children had the most intense medical, disability, and behavior problems. We wanted to know who was at the edge of the eligible/ineligible line. The family support agency claimed and this report verified, all children can live in families and be supported. In other words, after viewing the children in this report it would be difficult to imagine any child who would need to be institutionalized or served in a group setting other than a family.

Tasia is seven years old. She would be classified as profoundly retarded. She is totally blind --- she has no eyes. Her head has a large protrusion, an encephalocoele or sac about 7 inches in diameter, that is filled with spinal fluid. She has good muscle tone in her legs and arms; indeed she looks quite healthy, even strong although she is unable to sit up, stand, or walk. Her single parent foster mother hopes to begin working on having her develop self toileting, starting first with scheduled toileting. She may work too on self feeding and maybe on having her learn to stand. She needs total care. Tasia came to this home from an intermediate care facility; prior to that she had been a resident in a nursing home. She is the kind of child one sometimes sees in the infirmary of institutions. One of the family support workers noted, "these are the children everybody else calls the throw away kids."

Tasia was not the only "medically involved" child observed. Another child has been diagnosed as having anencephaly. This child, age 5, named Semantha, weighed 3 pounds and 2 ounces at birth. At age 5 she weighs 21 pounds. She has a shunt to control hydrocephalus. When she first entered the foster family, she was up 24 hours a day and cried a lot. Her adoptive mother believes that she was probably just being irritable because the shunt was malfunctioning. Today, Semantha lives with her adoptive family, a working class family that includes six other children, four of whom have severe retardation. Of these four,

all are incontinent, two must be fed through gastrostomy tubes, and one who screams loudly for several hours at a time. His mother calls this behavior "rage seizures": "he has episodes of screaming. I was going to say crying, but its really more than crying. Its unconsolable (sic)."

Another foster mother described how her own children, three sons and a daughter, were shocked at one of their two foster daughters' self abuse. She has been known to bite herself, break toilet seats, and hit. A birth family described their son Mathew as having dramatically limited their lives, keeping them from taking vacations or even going out of the house together. He is classified as having severe autism. His father remarks, "He's more self abusive now than he was. He'll beat himself in the head. He gnaws on his fingers. Yes, he has pretty sharp teeth." As with several other of the children observed, he is nonverbal. But he makes noises, most commonly a monotone groans. His father explains that if it gets too loud, they have to bring Mathew inside so that he does not disturb the neighbors. Sometimes, "the noise he makes...goes on for months."

At another home, a middle aged, working class couple provide a home for three adolescents, two who have severe intellectual disabilities and cerebral palsy and one with a moderate intellectual disability. The boy of the three also has severe behavior problems; when he first came to the home from an institution he would chew on his arm, wrecking his clothes and

creating sores on his arm. One of the girls weighed only 37 pounds at the age of 14.

In the other three families visited, the children had exhibited significant medical complications. Two eventually died and the third seems to be thriving. Nicky was healthy until the age of 19 months when he developed tremors, later diagnosed as a seizure, extreme low sodium, and then difficulties in breathing and swallowing and total physical deterioration that caused him to require a respirator. Another child, Sholanda, who was mentioned at the onset, was born weighing 10 pounds and 1 ounce. She had a rare condition that left her nasal passages blocked, characterized by rapid aging and retardation, and eventually required her to be put on a gastrostomy tube for feeding and a respirator for breathing. A third child, Timmy, also needed a tracheotomy to breathe in case because his trachea and esophagus were fused together from birth. He has one leg, a gastrostomy tube for feeding and a colostomy. When he was an infant, doctors thought he would be severely retarded, but at four years old he appears to be of normal intelligence.

Ability Over Disability:

Interestingly, the children's conditions, which in each instance seemed either difficult to manage behavior or medical problems, or both, were not the central theme of parents' comments. The parents spoke positively about the skills they had developed, for example to teach a son or daughter not to be self

abusive or to learn how to manage respirators and to keep tracheostomy and gastrostomy openings clean and functioning. But it was as if these were merely necessary steps on the way to realizing a normal family life. They tended to comment about their children's conditions by way of charting their progress. One father tells about how his son began to breathe on his own:

> Nick's doctor said, "Oh, he'll never breathe." Well sure enough he was home exactly one week, we took him out in the backyard because he's our son, just like our daughters. We had a plastic bag attached to his trach; we were 'bagging' him. I thought he had the hiccups. But the nurse said, "no, he's breathing." I said that can't be right. But that's when we began keeping a book (diary) on Nicholas.

This same family saw its son develop an ability to move his arms and legs; they bought a dog to motivate him and they played games with Nick, using balloons attached to strings and other objects that he could move. Such stories were repeated in each home. Timmy, the child with a colostomy, gastrostomy, tracheotomy, and one leg was as active as any of the other children in his neighborhood. The caseworker explained: "He has an artificial leg. He has a tracheotomy, but he talks. He can run and he rides a tricycle. He is enrolling in a typical nursery school."

Sholanda is a child who did not improve. In fact, as long

as she was alive, her condition seemed to get worse. Yet her parents speak of her strengths. They noted with pride that she would begin throwing up in the car each time that they would take her to the hospital, a sign of her awareness and of her resistance against going to a place that she regarded as hostile. Although she had a tracheotomy, her parents noted, "she was trying to talk". Her mother saw her as always saying something, trying to assert herself:

> I thought it was better her being at home than in the hospital. She would try to sit up. We tied her trach tube on, then she'd take it off. We'd tell her not to pull it out. My hand would be shaking, trying to get the tube back in, and she's deliberately hold her neck back like this so I couldn't get it in. I'd be fussing and she was laughing. Tholanda was in bed laughing. I'd say that wasn't right. She just laughed and smiled and then she'd kick her leg. She was trying to talk, you know. She couldn't really talk. But she could holler.
>
> She also started scooting around. They thought she would do nothing, but she got to the point where she was scooting up under the bed. She started getting a little active until around her spine she had problems. The doctors told us we had to keep her in bed. So we did that and she was getting mad.
>
> She was stubborn. If she didn't want to be bothered by

> the teacher who was coming here, she would get to crying till you let her have her way. We weren't sure if she could see, but her hearing would follow you wherever you were.

Kevin, Sholanda's father, seems to find a quality in Sholanda to offset each of her difficulties: she is blind, but she can hear; she cannot talk, but she can holler; she is in pain, but she has a sense of humor, she can laugh; she can do very little, but she can get her way. Not long after her appendectomy, she died. But her father recalls her time with the family as a good time:

> She definitely knew where she was at. When she heard her sisters she would smile. She was in a lot of pain. You know, man, she had a lot of problems. But just having her here and you know, just to show her that we loved her, you know, and for the short while, I thank God for that.

Such remarks pervaded the interviews. They bespoke admiration and certainly acceptance by the parents of their children. Serious health problems, extremely difficult behavior, severe intellectual disabilities were all problems to be accommodated and to some extent overcome. It is not pollyannish to say, even, that the families saw progress and hope where many people less connected with the lives of these families might only imagine tragedy, despair, and disappointment. Sholanda's father typifies this attitude:

> When she was in Children's Hospital they told us a lot of things, like "she'll never do this anymore, and she'll never be able to do that any more, she'll never be able to do this." Well, if that didn't destroy the confidence, we still believed. No it didn't destroy the confidence. I had seen different.

From the outside looking in, an observer might think that the families tend to romanticize their children's progress. Indeed all parents may do that from time to time. But what seems to occur is that parents, whether birth, adoptive, or foster parents, come to know their children so well that they see changes that others may not realize or appreciate. One family was more discouraged with its situation than the others. This was the family of Matthew, age 21 who had severe autism. His parents were concerned that he was still incontinent, still groaned a lot, and did not have a lot of things to do. They interested him. They were worried about his future, what would happen to him when he was no longer eligible for school and when he needed a place to live, perhaps a group home. But the very way this family approached his future, wanting to guarantee that he would be in a residence that would provide him with warmth, caring and training, suggested that the parents believed he was doing as well as he was because of how he had been treated by them. In other words, had he not lived at home, he could be a lot worse off, more self abusive, engaging in more self

stimulatory behavior. This family showed me Mathew's communication device with which he is able to communicate a few simple things, like food or play.

By living together, the families develop sensitivity to each other. A foster parent describes such an instance:

> Toni can say one word. She can raise her hand to say yes. Kerry will say "some juice please Mom." As soon as she says that, Toni will make a loud noise. So I'll ask her if she wants some juice, and she'll raise her hand. A couple of months ago we had supper and we got done eating and Kerry said "more spaghetti please." As soon as Kerry said that, Toni who was sitting between Dad and me, made loud noises. I said, "you want more spaghetti?" Then up shot her hand. Now, when Toni gets off the school bus (or is gotten off, since she needs to be wheeled in a wheelchair), and the minute I pick up my tea cup, she'll start with the noises. That's your clue to ask if she wants a drink. So she's figuring out ways to get her point across.

Even Semantha, the child diagnosed as having anencephaly, is described by her foster mother as being expressive, as interacting:

> She's vocalizing, not quite laughing. And she's kicking her legs. She just started doing that a little while ago.

This foster mother saw progress. She and other family members lament the fact that other people find it hard to see what they see. Her sister remarked for example, "if people aren't involved with a family or knowing children, they can't understand why they (her sister and brother-in-law or any foster parents) have them. Well what are you going to do? Are you going to kill them?" She believes that people cannot have an understanding of why a family would take care of a child like Semantha unless they can see the family and come to know Semantha. The foster mother for Semantha and four others with handicaps resents society's negative evaluations of children such as hers. She told us, for example, of a national television network news program portrayal of her family:

> the producer said that the newspapers say these children are going to be suffering and bedridden. He said he wanted to see what did happen. Well my children are not suffering and they are not bed-ridden. But that did not come across on television, not a bit. The whole show I felt was negative.

Part of the Family:

"You and grandpa can come but Tina can't come. She's not your family", a child announced to her grandmother. The grandmother is a foster parent. She took the comment in stride and offered a ready response: "Oh yes she is," she declared, "and I'm not coming if Tina can't come." As the foster mother

explained, Tina gets in the way as far as her granddaughter's concerned. "When you're five you don't really understand all that." The foster mother recalls the adjustment that her own children had to make when Tina first joined the family:

> At first it was, "that's some situation Mom." My sons were a little awestruck at the idea of the things she would do to herself and how she would injure herself that way. I'm sure there were times they resented her presence. They might have said, "we can't go and do this because of her." But, (actually) we haven't held back in many places.

For this family as for the other birth and foster families, that spirit of adjustment was more positive than mere resignation to the child with disabilities. True, there had to be a measure of family tolerance --- on several occasions, Tina broke toilet seats, including one at the family's relatives' house, for which the father promptly gave his brother cash for a new one. And there had to be a willingness to pull together: "I think its kind of a family affair. Everybody gets involved."

Nicky, one of the children who had become ventilator dependent, became the focus of his family's teamwork:

> Besides doing exercises with him, when it came to feeding times and stuff like that, well we all chipped in. It was just one of those things that "I'll do this, and you do this" and it always worked out super because when we

worked like that we had more time to work with Nicky too. As his mother explains, some of Nicky's care required group coordination:

> A lot of times you can't give a child a bath when he's hooked to a ventilator. You have to have someone bag (manual ventilating) and someone bath. You see, Blue Cross never thought of that. There were times when there were only certain things I could do when I was strictly Nicky's m[illegible] Nicky's nurse, or whatever I was doing for Nicky. It always took two people to sanitize Nicky's unit. One would have to bag, the other would have to sanitize the unit. The girls would get the things and put them in the bucket. We'd all have something to do.

Interestingly, Nicky [illegible]isters did not seem to regard his care as all work. His moth[illegible]plains:

> We coul[illegible]igure out wh[illegible]r kids wouldn't want to go shopping with us. But we found out what it was. Whenever we left the house, they would get Nicky out on the couch and they'd pretend they were like Dorothy Hammel. Nicky and the nurse would sit on the couch. The girls would do all these gymnastics and stunts. Nicky and the nurse would rate them, like a 10 or 9.5.

Several of the families also speak appreciatively of tolerant, accepting and helpful neighbors:

> We have neighbors that come u[illegible] (to camp in the country)

> the same weekends we do and Nancy (a foster child) can walk on her own to visit with them. They've been very accepting. Very, very, nice people with the girls.

While families adapt their lives to accommodate needs such as a child's exercise, cleaning a trachea opening, or keeping a ventilator going, they also report wanting the child to become a regular part of family life. This means participating where possible in household routines, like having a cup of tea in the midday, after school, helping to do the laundry, getting the mail, riding on the family lawn mower and helping to mow the lawn, going for weekends to the family retreat/camp, or spending a Saturday afternoon in the backyard or at the fishing pier:

> Nicky was home and no sooner than a week, we had him out in the backyard because he was treated just like all of us. If we were going to be there, he was going to be there. If we were going to be here, he was going to be here. He wasn't treated like a sick kid in the house. We even took him fishing. We took a bag and we bagged him. He was a typical kid fishing. We were close to a hospital if we needed a hospital, but he was to us stable. We knew him that well that we'd take him fishing.

Each family has its favorite leisure pastimes. Far from being always limited by the presence of a child with a disability, leisure seemed often to be enhanced or even motivated

by their being part of the family. One couple speaks of going out:

> Its fun. Toni "tells" the waitress she wants a piece of pie. The waitress heard me say, "what kind of pie?", so she said "and what kind of pie would you like?" Its cute to see her response. Toni'll look at her and make that funny noise. (With Toni you have to give her choices and then she can make a noise to indicate that she wants one of them.) Kerry orders for herself. She says if she wants a hamburger, spaghetti, or if she wants fish and chips. Noah is the exception because I have to order for him. Number one he doesn't talk. Number two, he has to have certain foods. But, oh they love it. We take them out all the time. We go to my mom's. We go to our best friends. We go to their place also.

One of the outings was a canoe trip, fully recorded in a family photo album. "You talk about fun" the foster mother recollects, "Noah laughed for a solid hour." They found a place where they could canoe in water that is only knee deep. It was a 90 degree day, but that does not seemed to have wilted their spirits. The foster mother invited her sister and her boyfriend along in order to have a second canoe. Before the canoe trip was over, the children were saying they had to do it again. Toni rode in a beanbag chair in the canoe --- Toni is classified as profoundly disabled, uses a wheelchair and is nonverbal. They all roasted

and ate hotdogs that day. The mother recalls, "we really had fun." In a sense, what seemed to be happening in this family would perhaps better be thought about as "finding a life together" (ie. having fun together, being together) than merely acceptance of the outsider, the children, into the world of the insider, the parents.

Parents: dividing the responsibility, mother's work:

Sholanda'a father, Kevin, had no previous experience with a disability other than a younger brother's asthma. T..is was foreign territory for her mother as well. Sholanda's parents learned of her disability when they took her to the hospital for an examination of her respiratory problems. Her condition deteriorated precipitously:

> We didn't know that she had problems.... She started taking sick. She was burning with a fever. So I took her to the hospital and they say its allergy. Then they get serious. When she came down with pneumonia. They did surgery and put a trach in her throat and she started coming around.

The parents had seen their healthy child become a very sick child, with irreversible brain damage and physical disabilities. Hospital officials did not want to let Sholanda come home. They were planning to send her to a nursing home or foster care. Given the disrepair of the home (oken furnace, hot water hea r, washing machine and dryer) and the parents' limited

education and economic means, the hospital officials thought the family could not provide her good enough care (ie. cleaning and suctioning of the trach, keeping the home clean and warm, reattaching the ventilator tube if it came loose). Eventually, with assertive encouragement from the family support caseworkers, Sholanda Senior went to the hospital and demanded the medical staff train her and then test her in trach care; "If I pass the test, I can bring my baby home; If I don't I can't." She did. The decision to try and bring Sholanda home was one that the Jones made together, although clearly they saw Kevin's role as being supportive and Sholanda Senior's as more focused on the day-to-day care of little Sholanda:

> The doctors wanted to put her in a convalescent home and at one time we almost decided to put her into a home. One night I said, "Sholanda, now look, what do you think? I'm looking out for your welfare baby. Whatever you want, I'm with you. Its me and you, Okay? Sholanda, its a job. Its 24 hours around the clock. What do you think?" She thought and she thought. And she said, "Kevin, I can do it. I can do it." I said, "Now, they looking at you being emotional Sholanda. There's a lot in it Sholanda," I said, "are you capable of taking that kind of responsibility?" She said, "Yes Kevin." That's the way it was.

Kevin worked hard, double shifts on an auto manufacturing

assembly line, to try and support the family. He became so tired from the heavy work schedule that he broke his arm in an industrial accident. Meanwhile Sholanda Senior took care of Sholanda. Kevin describes his wife's dedication:

> I've got to give it to her. Because you have some people that have a child like that... that don't want to take that kind of responsibility. She was really a champ with that. She was really with it. From the time even before Sholanda was even up, she was right there. We had all this medicine to give her. I don't know what it all was. But Sholanda Senior, she was a whiz. You would have thought she was a nurse. She had a chart to follow, on how much medication the baby was supposed to take. I said, "Sholanda, how do you do it?" And the other three girls she had to take up too. I'm telling you she's a whiz, man. She's a whiz. That woman put a lot of effort in her, man. I ain't telling you no lies, she put a lot of effort in that child, a lot of effort. She didn't half way sleep and she was in the room. She suctioned her and she wiped her nose. She would wipe her face a just stay there and talk with her. She would sleep in that room. She'd make a little mat on the floor and she would lay right there.

Kevin supported his wife, even to the point of predicting his daughter's imminent death and trying to ready Sholanda Senior for

it:

> We took the car and went shopping. When we was walking and I felt strange, like somebody was making me do it. I told her, I said, "Sholanda, are you prepared?" She said, "No." I said, "Well, you're going to have to. Junior is suffering and she's not going to be with us very long. I feel it Sholanda ... and I'm telling you... I'm not trying to be mean."

Like nearly all families of children with disabilities, Sholanda's life was transformed by the experience. It wasn't as if life had merely been interrupted. They became a different family unit and for that matter, different people. The experience seemed to draw them together. Interestingly, after her daughter's death, Sholanda senior secured a job working in a nursing home. She viewed this as a way of continuing the kind of care she had given little Sholanda. She became upset when she discovered that other workers at the nursing home did not seem to share her enthusiasm for providing highly personal, caring attention to the people in the home.

The fact that the mother was the principal care giver in the family is not unusual. In each of the eight families interviewed, all of the family members' lives are affected by the presence of a person with a disability, as is the fabric of family life. But the mothers consistently provide most of the direct care. Of course this is not a division of child care

> I mean he did not want our furnace. He used his tax money for the roofers and overtime money for the washer and dryer. They didn't want us to provide things for them. But in order to bring Sholanda home, we had to. It was difficult for Kevin. We sat him down and said that by not taking the money he was holding up getting Sholanda home.

In sharp contrast to the open, respectful give and take that had developed between Kevin and the caseworkers, he describes what it was like when a health officer arrived at the house to check on the conditions:

> I called them. And [illegible] 'Are you coming out here again?" She said, 'Well, I want to come out to your place but I'm wondering how you're going to act." I said, "Well, let me tell you. If you put me on the ropes, I'm going to bounce off to you. If you come here with sense, I'll talk to you with sense. You come here foolish and I'm going to treat you like you're foolish. You know, either way you want."
>
> "If you want to hurt me, I don't need no more pain. Cause I've got enough pain with my child sick. That's enough."
>
> There was too much tension. Okay? Because there was some doctors setting up there and they try to act so much

labor made unique by the presence of disability. Mothers have the principal role for childcare in general in this society. In one case, the father and mother as well as the mother's sister split the hours of vigilance when Mat is in the hospital, but when home, the mother is the one to stay home and provide the daily care. In the case of Mathew, labelled autistic, his father notes how difficult the son's behavior can be and that it is his mother who bares most of the responsibility for caring for him:

> Mathew is non-verbal, non-toilet trained, and very hyper. That noise he's making (a groaning hum) sometimes goes on for months at a time. The non-toilet training and noise are two things that drive us up a wall. When it stops you wonder what he's doing. You become a little bit concerned. And not sleeping at times, that's another problem. That's where we're coming from. And Gertrude, my wife obviously does the majority of the work taking care of Mathew.

For the birth families, having a child with severe disabilities is not something the parents chose. Rather it was something that came upon them, to which they adjusted. In terms of who was most affected by the presence of a child with a disability, mothers were, although in most of the families, the entire family was obviously involved. Mathew's father and mother, for example, had not had a vacation in ten years. They were planning a cross country car trip this summer with Mathew.

> intelligent and trying to make a big deal that Sholanda was not capable. And I just, if you love someone you're going to take care of that person.

Kevin's complaint was partly over how he and his wife were treated. Kevin wanted the doctors to give his wife her "props", by which he meant proper respect. It was offensive that she was treated as simple minded; it was frightening that this perception of his wife could prohibit them from bringing their daughter home. Kevin recalls what he told the doctors:

> She's got a little speech problem. She stutters a little bit. But that don't make her ignorant. That's why I said (to the doctors), "Who is you to judge?" I say, "She stutters a little bit; that don't mean nothing. That's not going to make it that she's not going to take care of her baby."

Kevin and Sholanda describe the struggle to convince health and hospital officials of their ability to care for their baby as a series of arguments, each having more to do with everyday stereotypes than with what kind of people they are or how they live:

> She (health department worker) said my house is not up to par. So we just got the roof fixed and they said they weren't sure I could take care of Sholanda. Then this lady comes to the house and said I was on drugs and I drink. Sir, I don't smoke. I don't drink. And I'm

They were worried about whether it would work. Also, they had decided not to move from their current house to a wealthier neighborhood for fear that Mathew might not be as accepted by a new set of neighbors. The father describes family life as having been significantly defined by their care for Mathew:

> We don't do many things around the house. Things don't get done. We're spending the better part of our lives, my life, Gertrude's life taking care of Mathew. Really. I've been severely criticized by a lot of people for doing this. Friends of mine. Well meaning friends. I'm not sure if they are right or wrong. I really don't know that. I just feel that Mathew had got to have something. A good life.

Foster parenting, for love or money?

The birth families differ fundamentally from the foster and adoptive families in regard to the nature of their choice about having a child with a disability at home. In terms of their role with the children, foster and adoptive mothers do many of the same things as birth mothers. They are the primary managers of support services; they are responsible for getting their children to medical appointments; they meet with diagnostic teams for planning the future of their children, and so forth. The fathers are active in care as well, but like their birth parent counterparts and like fathers in general, they also have jobs outside of the home. The primary difference between foster or

adoptive parents and birth parents is in their initial motivation for caregiving and parenting. Unlike for the birth parents, for the foster and adoptive mothers, becoming a parent was a way of becoming employed --- Macomb Oakland provides adoption subsidies to adopting families. One mother explains, "I did see it as a way to earn some money, be at home, to do things at home and with the family." At the same time, this parent saw herself benefitting from the job: "I love doing it. I've always liked helping people out. That's my high." She spoke of being a foster parent as an extension of other work she had done, for example years of working with the girl scouts. Another mother defined her choice to become a foster parent as a good one among limited options:

> It just presented itself. I suppose it was my boys; they weren't in the house all the time. They had their own activities. I wasn't having to take care of small children and I was, I suppose, at loose ends. Picking up socks and making beds isn't that stimulating. I'm not qualified to do a whole lot. I haven't been to college, so my options were somewhat limited. And at the same time, I did still have children at home. So working at a restaurant wasn't the best choice. I knew I could take care of children. That's why we thought of foster care. I heard that some of the children at the nursing home were available. I decided to give it a try.

It did not take long for each foster parent to find her motivation had broadened from desire for a job to one of becoming a parent. This fact was nowhere more apparent than in their attitudes about their own relations with the children's birth parents. The foster families welcomed consultation, collaboration and mutual strategizing with birth parents to get better services for their sons and daughters. But they resented having their role defined merely as a job. One mother explains her antipathy to this characterization:

> I think some of them see me as the hired help. I don't think they really have a good understanding of what their child's life is like. They make an appearance monthly, or every few months, and they look around and say, "I want it done this way; I want it done that way; you shouldn't have done this, etc." Then they go and you don't hear from them again.

Of course there can be legitimate differences of opinion between foster and birth parents. Even these can prove difficult to the foster parent. The ideal relationship, as far as foster parents are concerned, is to have birth parents with whom they can collaborate or from whom they feel support. They want parents with whom they feel they can talk about medical, treatment, education, and other problems as they occur. They want parents who are interested in knowing about the child's day-to-day life, parents who feel comfortable with their children. They do not

appreciate the birth parent who wants to hold back on a treatment or service that the foster parent believes would help the child. One foster parent gave an extreme example: "If they want the child to die, I think they should take the child home and do what they think is best. But to leave the child with me and say 'let her die in your home" is difficult." They do not merely want praise either. The parent who comes and admires the foster parent's success but then doesn't keep up regular contact with the family is seen as delinquent: "(they) said that we were doing a very good job with (their) son, and please continue to do so. Up they went and were gone. We haven't heard from them since. That was the Saturday after Christmas, 8 months ago." This same foster family was a little less critical, but nevertheless disappointed in a birth family that did not know how to show acceptance for their child with a disability: "She just watched. She didn't really have any kind of hands on contact until they got ready to leave" the mother noted. "You could tell they care about her, but they don't deal with her. Mom's a little bit better than the stepfather. There's a lot of pity on his part." In each of these instances, the foster parents feel protective of their children's feelings, and perhaps of their own as well.

A good relationship between foster and birth parents, from the perspective of the foster parents, is a mutually supportive one. Foster parents like it when the birth parents "pitch in."

One birth mother, for example, will come over to the foster mother's home, cook for the children, meet their school bus if the foster mother needs to be out, sew them clothes and go to doctors appointments. She is, in effect, an additional family support worker. Another parent reports on the benefit of having the birth family work with them to plan a strategy together in order to get their way in a school or habilitation planning meeting where the parents will be meeting with a room full of professionals.

The Mother's Role, Is It Fair?

In the case of Tasia, Sue became her foster mother and also had to secure another job outside of the home in order to qualify to be a foster parent. As a method of discouraging people from becoming foster parents for the wrong reason (i.e. to make money), state rules require that being a foster parent is not the sole source of income to the parent. This is a policy that would seem to discriminate against single people who want to become foster parents. Sue accommodated this rule by securing a job as a teacher's aide during the hours that Tasia was in school herself. Sue had never been married, had never been a parent, and was with her mother before she decided to become a foster parent. The family support agency provided Sue with 48 hours per week of in-home assistance from an aide to help her maintain Tasia at home. In other words, Sue needed substantial help from another person because she did not have other family members to

assist her.

The situation of this single, foster mother, and those of the other mothers raise the relationship of feminism to family support policy. We learn from these families that parenting a child with severe medical and behavioral needs requires a great deal of work, even with substantial agency or other support and that this work is not highly prized by society --- to a significant extent families must challenge social institutions and attitudes to accomplish it ---; it is not well compensated financially; it does not evoke attributions of high status for those who do it --- the families talk about how frequently people ask them why they do it, why they "give up" their lives for such children; it is mainly women's domain; and there is no competition within society to do it. In all these regards raising children with very significant disabilities parallels in somewhat exaggerated fashion the social context of childcare in general and to the status of women. Both are devalued. The questions this raises are equally apparent: if caring for severely disabled children is intrinsically important work, how could society come to see it as such? The women who do this work value it highly and feel annoyed that others do not share their perspective. How might society come to share their view? There is nothing in the nature of parenting children with disabilities that makes it women's work. How could it be made available also to men?[1]

III. WHAT DO FAMILIES WANT?

Caseworkers and families, finding a basis for an alliance:

A family support caseworker remarks:

> Both of those families that have lost a child are still really hurting badly. They have gone on with their lives and they don't show that side of them to everybody. But if you sit and you talk and you listen it comes out. I wish you could have seen the funeral that day. I could not believe instead of other people consoling the family, here's the family walking with and consoling and holding up the others.

Family support is a service to families, a way of helping them keep children with disabilities at home. It may involve providing them with financial assistance, medical or other equipment, counseling, the services of a physical therapist, assistance in locating a doctor or dentist who will care for a person with severe disabilities, case management, transportation, or a variety of other specific types of assistance. But it is more complicated than just offering a service.

The term "family support" has been part of the language of deinstitutionalization and community integration. It signifies a commitment to helping families become a principal alternative to large congregate care settings, like the big retardation institutions and nursing homes. And, as we will see, social change is very much on the minds of families and family support

case workers when they talk about their day-to-day lives. But the concept of family support also raises classic questions and dilemmas associated with the field of social work or casework. To what extent do family support personnel intrude into the lives of those whom they seek to assist? How do support caseworkers suppress their own values and attitudes concerning childrearing, family life, relationships, work, and other social choices? Should they suppress their own values and attitudes? Is the family support role to support the family or the child? What should be done when their needs conflict? Is the family support caseworker's job to be empathic with the family? Can they provide support if they are not empathic? What if they do not get along with the person? Should caseworkers expect to be thanked for their work? And, ultimately, can family support services escape becoming a form of social control whereby families are forced into being a certain way or making decisions of a sort that please or are demanded by caseworkers? If there is conflict between a caseworker and a family, how shall it be resolved, and on what basis? All of these questions flow from our central question: What do parents want from family support?

In this context, the caseworker must ask, "What is the proper role for supporting parents?" When a family support caseworker speaks almost reverently, certainly compassionately, of how a family handled the death of its child, finding strength to console friends and supporters, she obviously feels <u>they</u> have

deported themselves well. But it also reveals something about the caseworker's own deportment. This same caseworker admits that it is harder to feel so supportive of a parent who seems much more demanding and far less gracious. She commented on one parent:

> She is manipulative. She has worked her way through countless, countless nursing services, equipment companies and, to hear her talk, there has never been anyone who gave her a hand. There have been so many people who have helped her along the way. So many agencies. So many people. Individuals that she never credits. She's always got all of these things that people haven't done, you know. Its a little hard sometimes from that standpoint.

The caseworker remarked that she found it hard to provide family support and feel that nothing was enough for the parent. The caseworker also felt that the parent was wasteful, squandering equipment tubing, not washing certain supplies that could have been reused, losing an expensive prosthetic device --- the parent reported it stolen --- and ordering two, one from state and one from charity funds, of an expensive device that in the caseworker's view she only needed one of. Eventually, the family support workers transferred off this woman's case because of the feeling of frustration on their part, their perception of a personality conflict, and the parent's expressed dissatisfaction

as well. The Macomb Oakland agency facilitated transfer of the families needs to a caseworker who did not perceive the parent as difficult.

Predictably, caseworkers cannot help having favorite families. Among the qualities that these families were seen as having were: long term commitment to serving children with complex needs; ability and interest in trying to solve as many of the difficulties that come up as they can; a collaborative, problem solving attitude when children have difficulties; an ability to work with children who are perceived as having extremely severe needs; and a positive, cheerful attitude toward the children and also toward the caseworkers. But it is important to recognize that families have a different view. They do not want to have to abide by the caseworkers' own lifestyle preferences in order to warrant the caseworkers' best efforts. They do not feel they must earn the caseworker's friendship and respect. Parents want to be able to secure support without having to render themselves in a caseworker's image of an ideal parent.

One family that the caseworkers spoke glowingly of was Sholanda's, even though this family had been perceived by other agencies as possibly neglectful. In fact, the admiring caseworkers were more than a little uncomfortable with aspects of their home situation. The fallen roof, flooded basement, broken furnace and other physical conditions were easy to fix, but they

were concerned about the cleanliness of the house and questioned whether Sholanda senior might not be eligible for some of the cash benefits and medical insurance --- she was receiving --- she was registered for medicaid when she might also be eligible for private insurance:

> You work with what you find. Some caseworkers might come in with the attitude "I'm going to teach you. I'm going to show you. I'm going to do this for you." But we've never had (someone) tell us that we talk down to them or are judgmental. You pick up on the important things, that's all, like cleanliness and (the fact that) you can't cheat. But the rest of it you cannot change. We pulled no punches in telling Sholanda you've got to clean this up. You've got to keep this clean. You've got to do this or they (the health department) will take your child.

The caseworkers were quick to admit that this family's lifestyle might not be their own --- "they didn't even have a full set of dishes; I think they came from the mode where you go to MacDonalds for dinner." They described them as being "very anti-white in a sense... the whites always out to get them and that type of thing. They were very secretive." The caseworkers said this in a way that suggested that Kevin and Sholanda's reticence to be open with whites might have been justified in light of some of their experiences. In the same breath they explained why they

liked Sholanda and Kevin so much: "They really support each other." And, "for all his big hulkiness (body building), he is , its fantastic his love for his daughter... he speaks glowingly of her." The caseworkers focused their support on what the child Sholanda needed. As they came upon possible illegalities such as medicaid or welfare fraud or absence of safe housing conditions, they talked openly with the parents about them, identifying these as problems that had to be addressed and resolved, albeit with the caseworkers support, in order that Sholanda could be helped.

Parents Advise: Do what's needed, but don't take over:

The role of the support workers had to be circumscribed. Parents wanted the caseworkers not to intrude on the family. The caseworkers interpreted this to mean that they must keep their attention on the child. They could focus on conditions of the home and family interactions, but only as they might affect the child. Obviously love, cleanliness, warmth, were important elements. But the caseworkers did not see it as their business to influence other aspects of lifestyle, for example to tell Kevin and Sholanda to get married, even though such a thought might cross their minds. As they saw it, their job was to help the family help the child; this is an essentially functional approach of providing what is necessary. Also, help should be provided in an empathic, respectful way. The family support caseworkers recall admiringly how difficult it was for Kevin to accept their assistance even knowing how desperate he was:

terrified of needles. I don't do nothing.

Each question of their competence and life style meant a delay in bringing Sholanda home. The last delay meant that they could not bring her home by the Fourth of July holiday, the date they had hoped for. Eventually, this family prevailed, although it is not at all clear that they would have if they had not had the backing of the family support workers and if they had not, as one of the caseworkers explained, been willing to "fight every little issue until they (health and hospital officials) can't say 'no' anymore." The workers were supportive because they saw through outside appearances and stereotypes and focused on the family's ability. Finding the family competent, the support caseworkers stood by them continually insisting that other agencies (e.g. doctors, health department, welfare officials) refocus their attention as well on the issue of competence. The fact that Kevin and Sholanda had to repeatedly prove themselves competent is a theme common to people with disabilities, to poor people, to minorities, and to other marginalized people.

In the case of people with disabilities, it is a phenomenon not reserved only to those who are economically vulnerable. Nicky's mother, clearly middle class, recounts her surprise at being required to undergo a psychiatric interview at the hospital before being allowed to bring her son home:

> I couldn't figure out, why me. They were trying to see what type of people we were and if we could handle Nicky,

> if we could handle the problems that would come up, to see if we'd fall apart, end up in the crazy house. I just answered his questions. Hey, he's our son. Whatever it takes, we're going to do. I overcame that obstacle. You just go with the punches.

As I spoke with this mother and the other parents, it seemed clear that they shared a vision of what they considered a good professional, and they were quick to say when a professional failed to measure up. They wanted people like the family support caseworkers with whom they felt they could talk. They wanted doctors, dentists, therapists, and other professionals to be able to listen to them and be willing to consider their feelings as legitimate and valuable. Kevin felt grateful, for example, when medical officials immediately accepted his request that Sholanda not be given an autopsy: "Look doctor, I know she got tubes in her stomach, but she's my baby. I wouldn't want her to be cut no more." Knowing her death was imminent, the primary care doctor put a note in Sholanda's record recommending to the medical examiner that she not have an autopsy. In so doing, the doctor testified to the family's competence and honored the father's request.

The Good Professional:

Parents also speak of wanting professionals who feel they can learn something from parents, for example that Tasia responds

to certain stimuli, such as music, or that Nicky was able to breath on his own for short periods, acknowledging their assessment that he was feeling good or bad, healthy or sick: "the doctors couldn't understand how we knew him that well, but we could tell the doctors something was wrong. They got so they asked us." Nicky's mother recalls that the doctors would come into his hospital room and ask her, "'How does he look to you? How is his sodium?' And sure enough I'd be right."

The family support caseworkers felt their role was to assist the parents, hence they tended to ask the parents what they needed to do their job as parents. This meant that they put the parents in an expert role. The parents told them what was needed. It was natural then that the parents viewed the caseworkers as allies with whom they could discuss and evaluate different professionals, how to relate to the professionals, how to prepare medicaid paperwork, and what to ask for from the professionals. While the family support caseworkers were themselves professionals --- that is, they possessed particular skills and knowledge related to caring for children with disabilities, they had been trained in disciplines such as nursing and social work, and they were certified in their disciplines --- they practiced a version of professionalism that we might refer to as democratic professionalism; they saw their role as consultants to or collaborators with the families. True, they possessed some authority to influence a family's way of

raising a child or even whether a family would be allowed to raise a child with a severe disability, they tended to define their work with families as shared strategizing, as facilitators in the search for needed resources (fundings, supplies, and professional and nonprofessional assistance), and as "being there" to lend a voice of encouragement, to vent feeling, or just to hold hands.

The degree to which professionals could take parents seriously, learn from them, and cooperate with them determined whether the parents felt comfortable with them. And if the particular professionals provided a crucial service, for example trach care or respite, parents insisted on "good" professionals. One mother speaks with more than a little annoyance, perhaps even resentment, that a doctor interpreted a child's crying as a natural result of her anencephaly and hydrocephalus. The mother had cared for other children with hydrocephalus who had not displayed such behavior. Instead, she believed that the crying might be caused by discomfort from a malfunctioning shunt (a drain to inhibit spinal fluid buildup in the cranium). It turned out that the mother was correct. She resented the fact that it took the doctor so long to give her hypothesis serious consideration.

Another mother describes two different professionals' approach to her son's gastrostomy, tracheotomy, and colostomy care:

> I like the first nurse we had that stayed with us. She started off as an aide. She was going to school so she had not yet seen a trach, colostomy, or gastrostomy. But she was willing to work with me and show me what she was doing with Timmy. She went with me to the hospital and met his doctors. Between the both of us we learned a lot about my son.
>
> I had others that came in and thought they knew more than me. ... I need someone that I can train to take care of Timmy.

She wanted someone who would talk to her, learn from her, and work with her. Mrs. Clear[illegible] shared this view. She likes a therapist who actuall[illegible]es t the house and sees what you have to deal [illegible]th. She can be more realistic about what we need and what we can use."

This parent and all of the others prefer continuity in professional support. That is not always easy to find. The parents prefer dealing personally with in-home support staff. They feel uncomfortable having to rely on what they regard as "big bureaucracies". They want to get to know the assistant or specialist and for that person to know them and their children. In this regard, they speak regretfully of good assistants and specialists who have departed. One family mentioned the loss of a home health aide who had departed because she needed to attend

graduate school fulltime. Others "turn over" because the pay for an assistant is close to minimum wage and they receive better opportunities elsewhere.

The same kind of openness and shared decisionmaking that families desire in individual professionals and nonprofessionals is what they seek in family support agencies. Matt's father, for example, wants an agency that starts its involvement with a family by saying: "How can we help?" He resents agencies and professionals who come with a take-it-or-leave-it attitude: "(Don't send me) somebody who says 'we've got 10 services. Here they are. Take them or leave them.' Its not easy to ask for help. It's not easy to have strangers come into your home. But you want somebody to listen." He likes MORC because he perceives it as an organization that interacts with him rather than telling him. They ask, he explains, "How can we help?" After years of creating and belonging to parent support groups, some of which he and other families created to provide services that the professional community had not offered, he believes that families do not necessarily need or want what agencies give them. And not all families need the same things.

At another level, parents prefer and certainly look for professionals who <u>care</u> about their children. They want people who like their children and who treat them as important. They want professionals who see their children as more than "just another case." One mother recalls an instance of being treated

as a number: "'Where's your paper (medicaid paperwork)?' he said. Never even looked at Noah. He didn't even ask me why I was there. It was real obvious that he wasn't a bit concerned about Noah or his welfare." Another parent offers an example of a positive experience: "He's excellent because he's very concerned about her as a person and what is best for her." Lots of professionals may have useful, even crucial skills to render her daughter, but she likes those who "don't tell me only what they are doing, but why, and who offer options, so I can decide with them." She likes professionals who view her daughter as worthy of their time, energy, and skill. Like lots of parents, this one "shops" for good professionals; she notes that this means they are spread out over a broad geographic area, "from Flint to Detroit." She will sacrifice [illegible] and convenience to find the "good" professional (i.e. skilled, a good listener, [illegible] and willing to share in decision making.)

<u>Hard Services--- Equipment, Cash, Medical Care, Nursing, "whatever it takes", and People Willing to Break the Rules to Get Them:</u>

> The typical system is that you're reimbursed after the fact. But in a situation like hers, we upfront the money to her (e.g. 48 hours of respite services, cash for purchase of clothes for the child, a month's cash support of $1,200).

"A situation like hers" refers to the fact that MORC was placing a child with severe disabilities, including an encephalocele, and other complications with a 26 year old single, foster parent. The parent's only other income is the $6.00 an hour she earns as a teacher's aide. Failure to provide "upfront cash" might mean that the young woman could not see her way clear to be a foster parent. This would mean that Tasia would have to stay in a nursing home. Breaking from standard procedure is a veritable theme at MORC. The family support program does not usually supplant standard systems by which families are expected to secure assistance, but if the standard procedure involves delays in obtaining support, insufficient support, difficulty in obtaining the specific kind of support that would be most helpful, or an absence of support, any of which might prove debilitating to the family and child, then the family support program moves to fill the gap. The family support program will step in at times of crisis; it can serve as a funder of last resort.

Examples of family support's ability to break rank with standard procedures are numerous:

*Pay in advance for a wheelchair, prosthesis, or other equipment if a health department or social service department is too slow in processing a request.

*Assist with home expenses over and above a family cash support allowance of $250 per month in the case of a

birth family or $1,200 for a foster family, if there are conditions that warrant the extra payment.

*Provide 48 hour a week aide support in a home at extra expense, over and above the $40 per day medicaid waiver allowance to a single mother if such assistance is deemed necessary to allow the parent to manage a child with severe disabilities, particularly in the early stages of a parent's adjustment to raising a child.

The nature of a family's needs are extremely diverse. They may include, for example, a prosthetic leg, a wheelchair, sidelyer, bolster and wedge cushions, specially fashioned wheelchair inserts, a hospital style bed, a baby's crib or stroller, a hot water tank or house furnace, a generator, oxygen tanks, ventilator compressors, [illegible] supplies and suctioning equipment, and communication devices. Families typically have to wait months for some of these items, either because the suppliers need to fabricate them individually (e.g. as in the case of inserts or communication mounting apparatus) or because of delays in obtaining medicaid approval for the purchase. A foster mother explains the waiting process:

> Seating is always a big problem. This little chair over here or positioning equipment. The big problem is when decided what you need, everyone agrees on it, and then you submit it to medicaid. It (approval) takes months. It could be up to a year.

The family support staff will expedite approval or provide the advance payment if the delay is too long and too difficult to endure.

> If the child <u>really</u> needs the equipment, we get the approval or we pay for it. You really have to keep on their (Department of Social Services) tails.

The family support staff note that you have to be persistent with the paperwork and justifications:

> they'll (social services which administers medicaid reimbursement) reject something, so then you run it in a different way (different explanation or terminology) and they'll approve it.

In other instances, the parent explains,

> its the companies that are slow in processing, or they are slow in making it and its easy for them to (use the excuse) "medicaid didn't approve it yet" (or) "we're waiting for medicaid." Sometimes it takes a couple of months for the company to make a specialized chair, just to have it made.

Other services the families rely on include occupational therapy, in-home aides to help make dinner, bathe a child, feed the child or provide respite, home care training for the parents, psychotherapy, behavioral treatment services and consulting, consultation from a dietician, volunteer driving or other transportation, dental care, assistance in finding housing,

medical care, and physical therapy. Behavior specialists and respite service are especially critical to a family's success in keeping a severely handicapped child at home.

Tasia has a habit of putting her hands in her mouth. Susan, her foster mother, can give her a toy to hold, to occupy her hands, but then she puts the toy in her mouth. Susan tells her "no, take your hands out of your mouth" and can guide her hands away. But the behavior persists. Her next step is to contact a behavior specialist. With such a person she can develop a strategy: "we don't have a program written for it yet. That's one of the first things we're going to work on." Another child, Tina, presented her foster parents with physical outbursts. They too found that family support could provide them behavioral specialists:

> When Tina first came to us she was a very active young lady She still is. She's very self-abusive. A lot of things were happening and we were brand new to foster parenting and to being close to a mentally retarded person, especially with behavior problems. Special psychologists helped me deal with her behaviors and to calm her down.
>
> She would sit and bang her head against the wall. She would look in the corner where it was hard wood. We've panelled most rooms in our home since Tina's been with us. She would hit her head with her fist. In the head

and in the stomach., on her other arm , on her body. There were times she would stand and do a free fall, just let herself go on the bare, hard floor. I have not seen her do that in years.

I wasn't prepared at all for what we faced when Tina came. I learned that you don't spank and things like that. At one time a lady came once a week for a couple of hours. She sat with me. If Tina was well-behaved, we just talked. If Tina went into her act, she helped me keep myself out of it. I found out that I had to leave the area. Tina would look for me to be there, then she would continue. I had to get so I could handle it in my mind that I could leave when Tina started. It (the behavior) eventually has quieted down. She used to be on tranquilizers. She is no longer.

While the services of behaviorists are available, the parents look on these people as consultants and co-strategists rather than as people who can solve all problems. The idea of having someone to talk to about the difficulties is important to them and sometimes that seems to be all that caseworkers or behavior specialists can offer; sometimes the behavior does not improve. But the parent at least does not feel abandoned:

We have a psychologist assigned for any behavior problems. If I have a problem, a behavior problem, it just takes a phone call for help. In the beginning it

was difficult because he appeared to be in pain. I'm not convinced he isn't, but I've been told that he isn't in pain. It's really quite distressing. There isn't anything we can do for him. I think we've tried everything imaginable, from just leaving him alone to cuddling, feeding, wrapping him up, etc. Nothing works. He does tend to kick and thrash. He's hurt himself. Probably the best thing to do for him is to put him in his bed and take all his toys out. He likes a quiet environment. I think the cause is physical, not a real behavior (ie. acting out intentionally). A lot of times by putting him in his room it looks as though you're ignoring him. And yet that's probably the best thing to do for him.

Respite:

When we talk of respite, so often its from our perspective. We give them a weekend free during the month. Or we send somebody in to let them go shopping. We give them an afternoon free. (Then we say) 'look at what great things we're doing.' Actually, when you are dealing with this problem (of raising a child with very severe disabilities, and severe behavior difficulties) for 24 hours a day, its a heck of a lot of work. And its very frustrating. You need more than a break to get away and do the essentials. (Family support caseworker)

Parents agree. For some it is nearly impossible to find people to sit while they go out. The family support workers report that there is never enough money available for respite services. But the biggest difficulty seems to be in finding capable respite people or places. As we noted earlier, the parents in one family had not had a vacation away from their son in his 20 years with them. The reason is that they do not have respite services. Another family <u>did</u> get to go on vacation, but as they point out, the arrangements for respite were not worked out until two days before they were scheduled to leave:

> Our case manager made many calls. I did a lot of calling myself. One family would refer me to another. One preferred only boys. She (another foster mother) didn't mind behavior problems, but she only liked boys. Another would work with girls, but she was going to be on vacation during that period. For another, it coincided with an event she had going on. Finally, Tina went to a group home.

One father especially needed respite for several weeks while his wife was having and recovering from surgery. At first he had a respite worker coming in from 4:00 P.M. until 8:00 P.M. to meet his son after school and to help with household chores until he could arrive home from work. But that arrangement was found to be too expensive, so the father was forced to secure assistance from a less expensive agency. This time, however, the respite

help proved less than satisfactory:

> I had to wait on her (the respite worker). I had to give her supper. I set the table, made the supper and served it while she sat there like a bump on a log.

The respite workers he liked were from an agency that paid between $8.00 and $10.00 per hour and where supervisors held meetings periodically with respite staff to discuss the nature of their work and the expectations: "they problem solve together, you know, 'what do you do when that happens...'; they share successes; there's a sense of camaraderie." The father felt that when they had a person on whom they could rely, he and his wife could feel free to go out with friends at the spur of the moment without worrying. Some other families partially resolved the persistent respite problem by enlisting the services of an extended family or large nuclear family --- teenage children, uncles and aunts, or parents of the parents might become the parents' respite workers. Even though nearly every family could recall good experiences from time to time with respite workers, they all nevertheless shared the belief that, as one parent articulated, "the biggest void has been in respite care."

Throw Away Babies, Against the System; Allies With Whom To Transform the System:

> He was a throw away baby. He was one they would have just let die. According to medical standards, these are the kind that they would have (in years past) just, you

know, just let die. No feedings. That kind of thing. (Decisions not to feed or treat a child are now clearly illegal; although instances of less-than-aggressive care for some multiply disabled infants still exist).

As the family support caseworker's words suggest, families and caseworkers regard themselves in a struggle against societal norms. In fact, they are fighting disability-related discrimination (ie. handicapism) on two levels, in social institutions or social policy and in personal interactions. On the societal level, for example, they find themselves challenging standard definitions of who can live in the community or in a family, even who can be allowed to live at all. They see themselves challenging professional decisions to send certain children to state institutions or private, pediatric nursing homes. For those families who decided a decade or more ago to keep their severely disabled children at home, there were few services and little support. As one father recalls, "we had to go out with our hands out and say, 'please help care for my kid.'" They had to create schools. They had to transport their children to and from school. Invariably they even had to pay for schooling. Now, there are allies in the effort to find services.

Several of the families define their struggle to provide for their children as making policy. One family was the first in the state to force a private medical insurance agency to provide comparable benefits to families that wanted to keep a child who

is ventilator-dependent at home rather than in the hospital. A foster parent talked about her commitment to providing a home life for her child as complementary to the goal of closing down pediatric nursing homes, to make such institutions unacceptable places for raising children:

> The conditions weren't very good. You had a lot of children to take care of. So mostly you were just feeding and changing diapers and things like that. You couldn't work with them. You weren't trained to work with them. (The staff) used to feed the kids in (ways) to get them to eat in the shortest possible time. (Foster mother who had worked in a nursing home prior to adopting one of the children under her care.)

Tasia learned in the institution to put her head back and have food "poured" into her throat. As her foster mother explains, "It could have been very easy to asphyxiate." Now she is learning to eat more normally. A family support caseworker echoed a sense of urgency about bringing children out of the nursing home:

> I have friends (children) that were in Hillvale and I warned their relatives, asked their relatives, begged their relatives to please try and find another place. The food, well you get about that much food (a pinch). They were saving money on food. They give the lowest pay to workers. They don't get paid so they don't care about

> their work. That reacts on the patients.
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> ...
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> I finally said to the fellow in the state capital, "I don't care. I will call you every day and will report these things (e.g. unmedicated bed sore). If you do nothing about it, that's your business, but I'm not going to die and have Death say to me, 'what did you do with these kids that were in here?'"

Much like the families who say they "never backed off", who never took "no for an answer" about whether they could bring their children home and whether they could get the financial and other support they needed, the caseworkers speak of weathering the resistance to making placements of children out of nursing homes and hospitals into homes. One caseworker explains: "Yes, you get a lot of roadblocks... but if you are just persistent and you don't take "no" for an answer, and you tell them how you can fix any obstacle, then you do it." And, she notes, once such a placement has been made, the officials do not make it so hard the next time: "they are much more helpful; they kind of learn; they are willing to work with you, more cooperative."

Sholanda parents talk about the struggle to keep her out of nursing home as a struggle in which the family support caseworkers were their allies:

> They (hospital officials) wanted to put her into a convalescent home. I wouldn't go for that. (But) I just

> felt she wouldn't have got good treatment there as she would have got at home. Because we loved that child.
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> ...
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> We had many people against us. And though we was capable, (it was the caseworkers) who had faith in us. I really appreciated that. I really did.

Of course there are lots of conflicts that the families have with society, with other social institutions and people besides nursing homes and hospitals. In some of these, the parents feel that they are able to create change. In others they are not. In short, while family support is a crucial service to help them manage keeping seriously disabled children at home, it obviously cannot solve all problems, overcome all bureaucratic hindrances, or eradicate any and all disability related discrimination. Timmy's mother had visited a number of nursery schools and preschools in search of one that would accept him. None would: "They won't accept him because of his trach." Another family had participated in a fundraising campaign to get a van so that they could take their child throughout the community. But he too was not let into school. His mother wanted to wear a beeper so that if Nicky was in trouble with breathing, she could rush to the school. But the school was unwilling to hire a licensed practical nurse to assist in Nicky's care. The family decided that it would have to give up some of its allocation of a private nurse's time at home in order to have him in school. As the

mother put it, "we were tossing about in another battle (for schooling) when Nicky died. We would have continued the fight if he would have lived." The other foster children, all of them in the group of families we interviewed, were forced to attend separate schools for children with disabilities.

At the personal level families experience handicapism more emotionally, although it is essentially like social policy and institutional discrimination in that it bespeaks their status of being seen as different and perhaps even unwanted or unaccepted. A mother reports having her son stared at in a restaurant, an encounter that led her to thrust her son's artificial leg in front of the waitress and to say, "here is his leg, look." Children in Timmy's neighborhood play with him and accept him. His artificial leg, colostomy, gastrostomy, and tracheotomy do not keep him from having friends in the neighborhood or from being accepted. Yet encounters such as the one in the restaurant are not uncommon.

Obviously, parents find ways of coping with such insensitivity and rejection. Tasia's mother was asked by her daughter's school principal if she would have Tasia wear a bonnet to school and while she was at school, to cover her (admittedly disfiguring) encephalocoele. Tasia's mother explains:

> They (school officials) were concerned about parents of the other children in her room. They thought that these parents were still learning to accept their own

> children's handicaps, and somehow Tasia was supposed to be making it worse. There was some talk of putting her on the side so that they couldn't see her as well. The principal feels that 'Tasia has a right not to have people grossed out by her appearance.' That's his philosophy.
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> ...
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> My feeling is that yes there are times where maybe people aren't going to interact with Tasia on a regular basis. Like when we go to the store. These are not people who are going to get to know her So, I agree then. But if people are going to have to interact with Tasia on a regular basis, then there's no other way to get used to her appearance than to see her. There's no use in hiding her.

After consulting with her caseworker, Tasia's mother decided not to comply with the principal. People who would be around Tasia ought to feel comfortable with who she is and what she looks like. She would not cover Tasia or hide her from people who should be accepting of her. As for strangers, she decided to compromise, more for her own and Tasia's benefit than for the public. She would put a bonnet on Tasia when going to the store, because this involved meeting people on a onetime basis. She did not want to have to provide inservice training on attitudes about disabilities every time she and Tasia strolled down the grocery

store aisle. Being a foster mother meant having to endure a broad range of insensitivities and discrimination, but it also meant that since these were so frequent and numerous, to the extent that she had control over them she would decide where, when, and if to confront them.

IV CONCLUSION

The family support program of the Macomb Oakland Regional Center is unusual for its breadth of types of service, its flexibility, its assertive role in helping families get started and to stay together, and for the many lessons it holds for the idea of family support in general. This report describes family support through the experiences and testimony of eight families. What comes through again and again is the families' sense of what they want and what works and the caseworkers determination to try and be allies to the families and their children, on the families' terms.

The following is a brief summary of our findings:

*Children with the most severe physical needs or problems as well as those with extremely difficult behavior can be supported in families.

*Foster and adoptive families can be found for such children.

*Families often have a tremendous ability to see their childrens abilities and range of qualities and to be optimistic, even in the face of their life threatening conditions.

*Many families are able to integrate their children with very severe disabilities fully into the life of the family; characteristic of these families, integration is constant, purposeful, and unconditional; these same families wonder about the difficulty society at large has in creating a similar level of acceptance outside the family unit.

*Mothers are most often the primary caregivers to children with disabilities.

*Foster parents may initially view parenting as a form of employment (if they receive pay for their parenting) but in a matter of months love of their children seems to become their primary focus.

*Caseworkers can be most supportive by being least intrusive in families' lives and by focusing primarily on what the family and child need to make community integration work.

*Family support workers and parents do not always get along. A change of family support worker can sometimes alleviate the conflict.

*Families want services that ask "what do you want" rather than ones that say "here is what we offer, take it or leave it."

*Families want caseworkers who care about their children.

*Families want caseworkers who listen to them, strategize for services with them, and who will stretch the rules and "fight" the system to get them.

*Families want flexible support; sometimes they need a lot of support and sometimes they need little support.

*Families often need "hard services" like equipment, cash, nursing, respite, and transportation. They would like to have access to these services without having to negotiate with enormous bureaucracies and without having to constantly be grateful or feel like a "charity case."

*Some families want family support workers to help them effect social change.

*Families want support caseworkers who share information and who "problem solve" with them.

*Families want caseworkers with whom they can disagree without losing their respect or support.

*Family support does not change the fact that families often still feel alone and embattled. However, parents like having an ally.

*Family support does not make day-to-day living "incident free."

*Family support doesn't always change the system: health care/insurance, transportation, schooling may remain problemmatic.

*Even with family support, families still seek informal networks. Their own sources of information and their own solutions; they seem to know that the dream of comprehensive services and of a day when nobody "falls through the cracks"

is perhaps mythical.

*Family support can be a vehicle for parents supporting each other.

*Managing the equipment suppliers, getting them paid, filling out necessary paperwork, scheduling appointments and other such tasks can become a full-time job. Family support caseworkers can help facilitate these tasks.

*Families want to be in control in their home; they want to be able to decide when and in what form they need support.

*Family support works when children fit into the family and are part of the family.

*Family support must be founded on basic respect for families and for the right of children to live in families.

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